

**PARENT/GUARDIAN STUDY ID** 

DAUGHTER STUDY ID

DAUGHTER'S AGE

TODAY'S DATE

MONTH DAY YEAR

The LEGACY Girls Study

Follow-up #2 (at 12 months)

Mother/Female Guardian Questionnaire

For parents/guardians with daughters age 12 and older

Feelings, Thoughts & Behaviors

Self-administered

- A. Your daughter's feelings and behaviors
- **B.** Your feelings in the past week
- C. Your feelings and thoughts in the past month
- D. Your health behaviors
- E. Cancer screening and surgery
- F. Your thoughts and opinions about breast cancer
- G. Your family

This survey is going to cover several topics. The first set of questions may seem a little different than what you expected. They are not about health or breast cancer. They are questions often used in research to understand how children may act. Next are questions about how you think or feel, your health behaviors, and your opinions and experiences with breast cancer and your family relationships. You may skip any question you would rather not answer.

### SECTION A. YOUR DAUGHTER'S FEELINGS AND BEHAVIORS

**Directions**: On the pages that follow are phrases that describe how children may act. Please read each phrase and mark the response that describes how your daughter has behaved recently (in the last several months).

Select **Never** if the behavior **never** occurs. Select **Sometimes** if the behavior **sometimes** occurs. Select **Often** if the behavior **often** occurs. Select **Almost always** if the behavior **almost always** occurs.

**Please mark every item**. If you don't know or are unsure of your response to an item, give your best estimate.

		Never	Some- times	Often	Almost always
A1.	Calls other adolescents names.				
A2.	Cries easily.				
A3.	Complains of being sick when nothing				
	is wrong.				
A4.	Annoys others on purpose.				
A5.	Worries about making mistakes.				
A6.	Uses foul language.				
A7.	Cannot wait to take turn.				
A8.	Has stomach problems.				
A9.	Steals.				
A10.	Acts without thinking.				
A11.	Complains about being teased.				
A12.	ls nervous.				
A13.	Says, "I'm not very good at this."				
A14.	Drinks alcoholic beverages.				

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# F-2 Questionnaire #3 MOTHER 12+ y: 10-4-12

		Never	Some- times	Often	Almost always
A15.	Says, "Nobody understands me."				
A16.	Teases others.				
A17.	Is negative about things.				
A18.	Complains of shortness of breath.				
A19.	Threatens to hurt others.				
A20.	Worries about what teachers think.				
A21.	Sneaks around.				
A22.	Has poor self-control.				
A23.	Says, "I think I'm sick."				
A24.	Smokes or chews tobacco.				
A25.	Interrupts parents when they are talking				
	on the phone.				
A26.	Says "I hate myself."				
A27.	Tries too hard to please others.				
A28.	Has headaches.				
A29.	Says, "I get nervous during tests" or				
	"Tests make me nervous."				
A30.	Is in trouble with the police.				
A31.	Says, "I want to kill myself."				
A32.	Argues when denied own way.				
A33.	Changes moods quickly.				
A34.	Complains about health.				
A35.	Hits other adolescents.				
A36.	Worries about things that cannot				
	be changed.				
A37.	Breaks the rules.				
A38.	Acts out of control.				
A39.	Lies.				
A40.	Interrupts others when they are speaking.				

# F-2 Questionnaire #3 MOTHER 12+ y: 10-4-12

		Never	Some- times	Often	Almost always
A41.	Is easily upset.				
A42.	Worries about what other adolescents think	<. 🗌			
A43.	Complains of chest pains.				
A44.	Gets into trouble.				
A45.	Says, "I want to die" or "I wish I were dead.				
A46.	Bullies others.				
A47.	Seems lonely.				
A48.	Complains about pain.				
A49.	Loses temper too easily.				
A50.	Is fearful.				
A51.	Uses illegal drugs.				
A52.	Fiddles with things while at meals.				
A53.	Breaks rules just to see what will happen.				
A54.	Says, "Nobody likes me."				
A55.	Worries.				
A56.	Gets sick.				
A57.	Deceives others.				
A58.	Seeks revenge on others.				
A59.	Says, "I don't have any friends."				
A60.	Is afraid of getting sick.				
A61.	Is cruel to others.				
A62.	Disobeys.				
A63.	Disrupts other adolescents' activities.				
A64.	Lies to get out of trouble.				
A65.	Is sad.				
A66.	Says, "I'm afraid I will make a mistake."				
A67.	Expresses fear of getting sick.				

### SECTION B. YOUR FEELINGS IN THE PAST WEEK

The next several questions are about how <u>you</u> have been feeling. For each item please check the reply that comes closest to how you have been feeling in the past week. Don't take too long to think over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

B1. I feel tense or 'wound up':

_	Most of the time
	A lot of the time
F	From time to time, occasionally
1	Not at all

B2. I still enjoy the things I used to enjoy:

Definitely as much
Not quite so much
Only a little
Hardly at all

- B3. I get a sort of frightened feeling as if something awful is about to happen:
  - Very definitely and quite badly
    Yes, but not too badly
    A little, but it doesn't worry me
    Not at all
- B4. I can laugh and see the funny side of things:

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

B5. Worrying thoughts go through my mind:

A great deal of the time
A lot of the time
Not too often
Very little

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- B6. I feel cheerful:
  - Never
     Not often
     Sometimes
     Most of the time
- B7. I can sit at ease and feel relaxed:
  - Definitely
    Usually
    Not often
    Not at all
- B8. I feel as if I am slowed down:
  - Nearly all the time
    Very often
    Sometimes
    Not at all
- B9. I get a sort of frightened feeling like 'butterflies' in the stomach:
  - Not at all
     Occasionally
     Quite often
     Very often
- B10. I have lost interest in my appearance:
  - Definitely
  - I don't take as much care as I should
  - I may not take quite as much care
  - I take just as much care as ever
- B11. I feel restless as if I have to be on the move:
  - Very much indeed
    Quite a lot
    Not very much
    Not at all
- B12. I look forward with enjoyment to things:
  - As much as ever I did
     Rather less than I used to
     Definitely less than I used to
     Hardly at all
- B13. I get sudden feelings of panic:

Very often indeed
Quite often
Not very often
Not at all

B14. I can enjoy a good book or radio or television program

Often
Sometimes
Not often
Verv seldom

#### SECTION C. YOUR FEELINGS & THOUGHTS IN THE PAST MONTH

The questions in this section ask you about your feelings and thoughts during the last <u>month</u>. For each question, please tell us how often you felt or thought a certain way.

- C1. In the last month, how often have you felt that you were unable to control the important things in your life?
  - Never
    Almost never
    Sometimes
    Fairly often
    Very often
- C2. In the last month, how often have you felt confident about your ability to handle your personal problems? I am not asking how often you have had personal (work, friends, family) problems, but how often when you had a problem you felt confident to handle it.

  - Almost never
  - Sometimes
  - Fairly often
  - Very often
- C3. In the last month, how often have you felt that things were going your way?
  - Never
    Almost never
    Sometimes
    Fairly often
    Very often
- C4. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?
  - Never
    Almost never
    Sometimes
  - \_\_\_\_\_ Fairly often
  - Very often

### **SECTION D. YOUR HEALTH BEHAVIORS**

Now we are going to switch gears and ask you more specific questions about some of your health behaviors.

D1. When you are out in the sun, how often do you wear sunscreen?

Never
Rarely
Sometimes
Most of the time
Always

D2. During the past 30 days have you had at least one drink of an alcoholic beverage, such as beer, wine, malt beverage or liquor?

Yes		
$N_0 \rightarrow$	GO	7

No  $\rightarrow$  GO TO QUESTION D3

D2.a) During the past 30 days, how many days per week or per month have you had at least one drink of an alcoholic beverage?

\_\_\_\_days per week **or** \_\_\_\_\_days in the past 30 days

don't know, not sure

D2.b) During the past 30 days, on the days that you drank, how many drinks did you drink on average? One drink equals one 12 oz beer, one 5 oz wine, or 1 shot of liquor.

\_\_\_\_drinks per day

D2.c) Considering all types of alcohol, how many times in the past 30 days did you have four or more drinks on one occasion?

\_\_\_\_\_ times

D2.d) During the past 30 days, what is the largest number of drinks you had on one occasion?

\_\_\_\_drinks

I don't know

- D3. How would you describe your body weight?
  - very underweight
  - slightly underweight
  - about the right weight
  - slightly overweight
  - very overweight

- D4. Which of the following are you trying to do now?
  - lose weight
  - gain weight
  - stay the same weight
  - not trying to do anything about my weight
- D5. During the past 7 days, how many times did you eat fruit? Do not count fruit juice.
  - I did not eat fruit during the past 7 days
  - 1 to 3 times during the past 7 days
  - 4 to 6 times during the past 7 days
  - 1 time per day
  - 2 times per day
  - 3 times per day
  - 4 or more times per day
- D6. During the past 7 days, how many times did you eat green salad or other vegetables?
  - I did not eat green salad during the past 7 days
  - 1 to 3 times during the past 7 days
  - 4 to 6 times during the past 7 days
  - 1 time per day
  - 2 times per day
  - 3 times per day
  - 4 or more times per day
- D7. During the past 7 days, how many times did you eat sweets (candy, cookies, cake, ice cream, pastry, etc)?
  - I did not eat sweets during the past 7 days
  - 1 to 3 times during the past 7 days
  - 4 to 6 times during the past 7 days
  - 1 time per day
  - 2 times per day
  - 3 times per day
  - 4 or more times per day
- D8. During the past 7 days, how many times did you drink a can, bottle, or glass of soda or pop, such as Coke, Pepsi, or Sprite? Do not include diet soda or diet pop.
  - I did not drink soda or pop during the past 7 days
  - 1 to 3 times during the past 7 days
  - 4 to 6 times during the past 7 days
  - 1 time per day
  - 2 times per day
  - 3 times per day
  - 4 or more times per day

- D9. During the past 7 days, how many glasses of milk did you drink? Include the milk you drank in a glass or cup, from a carton, or with cereal.
  - I did not drink milk during the past 7 days
  - 1 to 3 glasses during the past 7 days
  - 4 to 6 glasses during the past 7 days
  - 1 glass per day
  - 2 glasses per day
  - 3 glasses per day
  - 4 or more glasses per day
- D10. During the past 7 days, how many times did you eat fried food (French fries, fried chicken, bacon, potato chips, etc.)?
  - I did not eat fried foods during the past 7 days
  - 1 to 3 times during the past 7 days
  - 4 to 6 times during the past 7 days
  - 1 time per day
  - 2 times per day
  - 3 times per day
  - 4 or more times per day
- D11. During the past 7 days, how many times did you eat red meat (hamburgers, steak, barbecue, beef tacos, etc.)?
  - I did not eat red meat during the past 7 days
  - 1 to 3 times during the past 7 days
  - 4 to 6 times during the past 7 days
  - 1 time per day
  - 2 times per day
  - 3 times per day
  - 4 or more times per day

The next several questions are about cancer screening and surgery.

E1. Have you had a bilateral mastectomy (both breasts removed) either for treatment or prevention of breast cancer?

□ No  $\rightarrow$  Continue □ Yes, treatment related  $\rightarrow$  Go to E6 □ Yes, prevention  $\rightarrow$  Go to E6

E2. Have you had a screening mammogram in the last 12 months?

] I have never had a mammogram  $\rightarrow$  Go to E3

E2.a) My last screening mammogram was \_\_\_\_\_ years ago.

E2.b) I have a screening mammogram every year.

E3. Do you get breast MRI to screen for breast cancer? A breast MRI is a procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body.

☐ Yes  $\rightarrow$  Go to Question E3.a ☐ No  $\rightarrow$  Go to Question E4

E3.a) My last breast MRI was \_\_\_\_\_months ago *or* \_\_\_\_years ago.

E4. Have you had a breast exam performed by a health care professional in the last 12 months?

Yes	$\rightarrow$	Go to	Question	E4.b
No	$\rightarrow$	Go to	Question	E4.a

- E4.a) My last clinical breast exam was \_\_\_\_years ago
- E4.b) I have a clinical breast exam every year.



E5. Have you done a self-breast exam in the last month?

🗌 Yes	s → Go i	to Ques	tion l	E5.b
🗌 No	$\rightarrow$ Go t	o Ques	tion E	E5.a

E5.a) My last self-breast exam was \_\_\_\_\_months or \_\_\_\_\_years ago.

E5.b) I perform monthly self-breast exams.

$\square$	Never
	Rarely
	Sometimes
	Often
$\square$	Always

E6. Have you had your ovaries removed?

No
Yes, to prevent cancer
Yes, to treat cancer
Yes, for other gynecologic or medical reasons

**SECTION F. YOUR THOUGHTS & OPINIONS ABOUT BREAST CANCER** 

F1. Next are some sentences about thoughts and feelings you may have had in the last seven days. Please check each item indicating how true these comments were for you in the past seven days. If they did not occur during that time, mark "not at all."

		Not at all	Rarely	Sometimes	Often
F1a.	I thought about breast cancer when I didn't mean to.				
F1b.	I tried to remove breast cancer from my memory.				
F1c.	I had waves of strong feelings about breast cancer.				
F1d.	I stayed away from reminders of breast cancer.				
F1e.	I tried not to talk about breast cancer.				
F1f.	Pictures about breast cancer popped into my mind.				
F1g.	Other things kept making me think about breast cancer.				
F1h.	I tried not to think about breast cancer.				

	How much do you agree or disagree that	Disagree Strongly	Disagree	Neither Agree Nor Disagree	Agree	Agree Strongly
F2.	If a woman has a family history of cancer on her <b>father's</b> side of the family, she has an increased chance of developing breast cancer					
F3.	If a woman has a family history of cancer on her <b>mother's</b> side of the family, she has an increased chance of developing breast cancer					
F4.	Even if a woman has a family history of cancer, she may <b>not</b> develop cancer.					

- F5. Out of 100 women who get breast cancer, how many have inherited breast cancer?
- F6. Now consider the likelihood for **any** woman to get breast cancer. How many women out of a group of 100 from the general population, do you think will get breast cancer at some point in their lives?
- F7. Now, we would like you to consider women who have a family history of breast cancer. How many women out of a group of 100 women with **a family history of breast cancer** will get breast cancer at some point in their lives?
- F8. Are you familiar with the breast cancer genes, BRCA1 and BRCA2?
  - $\Box Yes \\\Box No \rightarrow Go to Question F9$

F8a. Have you received genetic counseling?

Yes
No

F8b. Have you had genetic testing for BRCA1 and/or BRCA2?

□ Yes  $\rightarrow$  Continue □ No  $\rightarrow$  Go to Question F8e.

F8c. IF YES: Did you receive the test results?

Yes
No

F8d. IF YES: Can you please tell us your results?

] Negative (no mutation)
Positive (a mutation was found)
Refuse

F8e. Has anyone in **your** family (blood relatives) been told he or she has a BRCA 1 or BRCA 2 mutation?

Yes
No
l don't know

F8f. Has anyone in your daughter's father's family (blood relatives) been told he or she has a BRCA 1 or BRCA 2 mutation?

Yes
No
I don't know

- F8g. Now, we would like you to consider women who have a change in a breast cancer gene. How many women out of a group of 100 women with a change in a breast cancer gene will get breast cancer at some point in their lives?
- F9. Have you ever had breast cancer?



No individual has the same likelihood of getting cancer as the "average person" in the population. Given that you are a unique person, this section asks you what you believe your likelihood of getting breast cancer or getting breast cancer again.

F10. What do you think the chances are that YOU will get breast cancer (again) before age 70? (0-100%)

%.

F11. My chances of getting breast cancer (again) at my age are (0-100%) \_\_\_\_\_%

F12. If I were to get breast cancer (again), I expect it will be at least years before I get breast cancer. (Please write the number of years).

- F13. Do you think your odds of getting breast cancer *(again)* are the same or different than those of the average woman? I think my odds are:
  - Much lower
    A little lower
    The same
    A little higher
    Much higher

Now we are interested in your thoughts and opinions about things that could prevent or delay breast cancer in women. Again, we are not looking for any particular answer, but are interested in what YOU believe. *How much do you agree or disagree that...* 

		Disagree Strongly	Disagree	Neither Agree nor Disagree	Agree	Agree Strongly	l don't know
F14.	I believe that women can do things to prevent or delay getting breast cancer.						
F15.	I believe that women can do things to prevent or delay getting breast cancer EVEN if they have a family history of breast cancer.						
F15a.	<i>Only answer if you are familiar with BRCA1/2; others go to F16:</i> Even if a woman has a change in						
	a breast cancer gene, she can do things to prevent or delay getting breast cancer.						
F16.	I believe <b>that I</b> can do things to prevent or delay getting breast cancer.						
F17.	If a woman leads a healthy lifestyle, I believe she can prevent or delay getting breast cancer.						
F18.	Even if a woman has a family history of breast cancer, leading a healthy lifestyle will prevent or delay breast cancer.						
F18a.	Only answer if you are familiar with BRCA1/2; others go to F19: Even if a woman has a change in a breast cancer gene, leading a healthy lifestyle will prevent or delay breast cancer.						
F19.	If <b>I lead</b> a healthy lifestyle, I believe I can prevent or delay getting breast cancer.						

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		Disagree Strongly	Disagree	Neither Agree nor Disagree	Agree	Agree Strongly	l don't know
F20.	Exercise is effective in preventing or delaying breast cancer for women.						
F21.	Exercise is effective in preventing or delaying breast cancer for women with a family history of breast cancer.						
F21a.	Only answer if you are familiar with BRCA1/2; others go to F22: Exercise is effective in preventing or delaying breast cancer for women with a change in a breast cancer gene.						
F22.	Exercise can help <b>me</b> prevent or delay breast cancer.						
F23.	A healthy diet can help women prevent or delay breast cancer.						
F24.	A healthy diet can help a woman prevent or delay breast cancer, even if she has a family history of breast cancer.						
F24a.	Only answer if you are familiar with BRCA1/2; others go to F25: A healthy diet can help a woman prevent or delay breast cancer, even if she has a change in a breast cancer gene.						
F25.	A healthy diet can help <b>me</b> prevent or delay breast cancer.						
F26.	I feel that a woman's relationships with her family might improve if she gets breast cancer.						
F27.	I feel that a woman's relationships with people outside her family might improve if she gets breast cancer.						
F28.	I feel that a woman can maintain her social activities if she gets breast cancer.						
F29.	I feel that a woman can continue working at a job (outside the home) if she gets breast cancer.						
F30.	I feel that a woman can maintain her family responsibilities if she gets breast cancer.						

- F31. I believe breast cancer is curable. Do you...
  - Disagree strongly
    Disagree
    Neither agree nor disagree
    Agree
    Agree strongly
- F32. I believe science will find a cure for breast cancer in:

s

#### **SECTION G. YOUR FAMILY**

This section contains a number of statements about families. Read each statement carefully, and decide how well it describes your own family. You should answer according to how <u>YOU</u> see your family. Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have trouble with a statement, answer with your first reaction.

	How much do you agree or disagree that	Strongly agree	Agree	Disagree	Strongly disagree
G1.	Planning family activities is difficult because we misunderstand each other.				
G2.	When someone is upset the others <i>know</i> why.				
G3.	In times of crisis we can turn to each other for support.				
G4.	We cannot talk to each other about the sadness we feel.				
G5.	You can't tell how a person is feeling from what they are saying.				
G6.	Individuals are accepted for what they are.				
G7.	People come right out and say things instead of hinting at them.				
G8.	We avoid discussing our fears and concerns.				
G9.	It is difficult to talk to each other about tender feelings.				

	How much do you agree or disagree that	Strongly agree	Agree	Disagree	Strongly disagree
G10.	We can express feelings to each other.				
G11.	We talk to people directly rather than through go-betweens.				
G12.	There are lots of bad feelings in the family.				
G13.	We often don't say what we mean.				
G14.	We feel accepted for what we are.				
G15.	Making decisions is a problem for our family.				
G16.	We are frank with each other.				
G17.	We are able to make decisions about how to solve problems.				
G18.	We don't get along well together.				
G19.	We don't talk to each other when we are angry.				
G20.	We confide in each other.				
G21.	When we don't like what someone has done, we tell them.				

- G22. In the last 12 months, has your daughter received care for a psychological condition (has she seen a therapist, counselor or psychiatrist)?

☐ Yes ☐ No  $\rightarrow$  Go to "End of Questions"

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G22.a	If yes, please	explain	(what type c	of care/did	she take an	y medication)	17

G22.b If yes, is she still receiving treatment?

Yes
No

End of Questions That is the end of this group of questions. Thank you!